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Breathlessness: the rift between objective measurement and subjective experience

Havi Carel

Breathlessness is a common term, familiar to all of us. Who hasn't felt breathless when running to catch a bus or rushing up several flights of stairs? It's a sensation we all recognise and yet most people give it very little consideration. Until I became ill with a respiratory disease (lymphangioleiomyomatosis, or LAM) I never gave breathlessness – or indeed breathing – more than a passing thought.

And that's because I had never previously experienced severe, pathological breathlessness. This debilitating, paralysing breathlessness cannot be compared to healthy breathlessness. They are qualitatively different. In healthy breathlessness you are in control; you are far from that liminal space where life is squeezed out of you and death beckons. Healthy breathlessness might tell you that you are challenging yourself physically, getting a good workout. Many people describe it as exhilarating. But regardless of how much you exert yourself, healthy breathlessness never feels threatening. You decide how breathless you want to be; you control it, not the other way around.

In contrast, pathological breathlessness descends upon you, paralysing you. Until you get that breath in nothing else can happen. Nothing else matters. Your world closes in on you and nothing is present except the terrible need to breathe. To get more air in and out and slowly to regain control over the panting and panic that have taken over.

Whenever I try to explain to healthy people what it is like to be so breathless I feel I have failed. The sensation is so utterly singular, so extreme, and yet so invisible to the external eye, that it is difficult to convey. On the other hand, so much is known about lungs. Physicians, physiologists and respiratory nurses know how to measure lung capacity, how to look after lungs with clean air and exercise, how to treat many respiratory diseases including infections. We know the processes that govern the intricate process of gas exchange and understand in detail the mechanics of breathing. Clinical medicine, physiology, and anatomy have accumulated an enormous amount of objective knowledge about respiration and lung structure and function. But the sensations of extreme breathlessness remain opaque in many ways.

This rift may be at the core of a common complaint sounded by patients, that their doctors 'don't listen' or 'don't really understand'. Is it possible to understand the extent of the fear and debilitation of pathological breathlessness without ever experiencing it? Can respiratory physicians truly empathise with their patients' suffering without having had those experiences themselves?

We cannot, of course, expect physicians to have first person experience of every disease they treat. But what we can do is illuminate the gap and address it by contrasting the two

perspectives. For the physician, breathlessness is a symptom. It is a physiological *sensation* (which may have a psychological manifestation), a physical phenomenon anchored in the respiratory system.

For the respiratory patient, pathological breathlessness is an overwhelming *experience*. Something that determines her every waking move, haunts her at night, controls and paralyses her with the constant threat of suffocation, sometimes with little or no warning, evolving into an invisible monster whose arms wrap around her chest, tightening its grip in ways that are unimaginably frightening and mostly beyond her control.

This demonstrates the deepest rift in medicine: a rift that is a fundamental truth about the limits of objective knowledge. There is a deep difference between the *objective* domain of physical bodies, disease and physiological dysfunction and the *subjective* experience of it. There is a gap between symptom and experience, between physiological disease and how it is lived by people.

Respiratory function tests measure many parameters of breathing. Such tests measure the amount of air inhaled and exhaled; the residual volume; the rate of gas exchange; the tidal volume; the forced expiratory volume per second, and so on. You'd think such tests can measure everything; but they cannot. The tests measure only what is measureable.

However, what is measured bears little relationship to what really matters to respiratory patients: what they can or cannot do, how tired they get doing it, how long it will take them and how hard it will be. What is still possible and what is no longer possible. How their everyday will be affected by their illness and what they will have to give up because of it. In short, how their future lives will play out in the shadow of illness.

This is a fact that has troubled respiratory physicians for many years: the lack of correlation between a patient's lung function and her real-life function. Physicians often point out a puzzling phenomenon: one can see two patients with the same lung function (measured objectively); one patient is active, goes out every day, and does many things healthy people do such as work and raise children. The other patient, with the same measured lung function, is severely disabled, housebound, and does very little independently.

How can this be?

The answer I propose here is anchored in a philosophical puzzle that has troubled philosophers for millennia. The puzzle involves thinking about the relationship between objective facts and subjective sensations, which is sometimes called 'the problem of consciousness.' Here is the problem: how can we relate objective facts about, say, seeing the colour red, to the subjective sensation of seeing a red rose? At some point, scientific explanations about rods and cones, light, and the optic nerve will end but they will never even come close to giving a colour-blind person reading them the *sensation* of seeing red. This 'what it is like'-ness is critical not only for philosophy but for medicine too. Because it points to a crucial fissure in the fabric of medicine: the gap between what medicine can

measure, examine and document about a particular health condition vs. the lived sensation and experience of living with that condition. There is a fundamental difference between these two domains.

What can clinicians and patients do about it?

First, there is a need to recognise the rift and clearly distinguish the two domains. We can do this by using the term ‘disease’ to refer to physiological dysfunction, while reserving the term ‘illness’ for the experience of disease, how it is lived by a particular person. This will make the gap between the two dimensions clear.

Second, there is a need to recognise the role this rift plays in clinical practice. For example, it may cause miscommunication between patients and physicians. Might they be talking about two different entities, as philosopher of medicine SK Toombs has argued? According to Toombs, the physician refers to the disease entity, whilst the patient’s reference point is the experience of that disease, how it has affected them, ie, by being painful, disturbing their sleep, and so on.

Finally, it would be useful to bring this rift and its effects into the awareness of practising physicians in their every interaction with patients. The disease remains opaque for most patients. They don’t have the knowledge to understand fully or contextualise the disease process. But the illness is what they live with (and in) day after day, sometimes for many decades. Thus the ‘patient expert’ is expert by experience, not by virtue of having medical or theoretical knowledge. The challenge is learning to use that expertise in a way that complements objective knowledge, rather than being seen as challenging it.

Ultimately, the experience of breathlessness is a universal one. We all die, and when we die we cease to breathe. Witnessing those final hours of laboured breathing are often distressing for family members seeking to support a loved one. Imagine doing that breathing, labouring away towards death. That is pathological breathlessness at its extreme. We should think about pathological breathlessness more, appreciate it as part of the end of life and as an experience we all go through, just like the experience – whether remembered by anyone or not – of taking a first breath when born.

Pathological breathlessness can serve as a *memento mori* not only reminding us of our mortality and the universality of death, but also of the pivotal role of breathing in life. This dual significance is mirrored in the rift between objective facts and subjective experience: breathlessness is not just a symptom but an experience. It is not only a physiological function but an experience rooted most deeply in our consciousness and sense of being alive. We must be able to hold both aspects and have them both present in the clinic.

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